Bridging the gaps between health, social and local services to improve care of people living with rare and complex conditions
The serious unmet social needs of people with a rare disease and their families affect their dignity, autonomy and other fundamental human rights expressed in the Universal Declaration of Human Rights and in the UN Convention of the Rights of Persons with Disabilities.
The needs of people living with rare diseases require coordinated multidisciplinary care

In most countries the care pathways are not structured

*Image used for illustration purposes. Source: Nationella Funktionen Sällsynta Diagnoser, Sweden*
European Commission Expert Group Recommendations to Support the Incorporation of Rare Diseases into Social Services and Policies (2016):

«4. MS should promote measures that facilitate multidisciplinary, holistic, continuous, person-centred and participative care provision to people living with rare diseases, supporting them in the full realisation of their fundamental human rights.»

Unanimously adopted by representatives of all EU Member States

Next Step
Moving from the recommendations to the implementation

INNOVCare

2015-2018
Bridging the gaps between health, social and local services to improve care of people living with rare and complex conditions
The dilemma

People Living with a Rare Disease and their Family

Healthcare

Social & local care and support
Call for proposals from EC DGEMP (2014) - “Social policy innovation”

• Focus on one stop shop services & case handlers
• Over 200 projects submitted - 7 selected
• INNOVCare is the only project on health/disability and with European scope

Time frame: 36 months - 01/10/2015 to 30/09/2018

Consortium:
• 8 partners, 6 countries - Spain, France, Slovenia, Romania, Austria, Sweden
• Main Applicant: MSSSI Ministry of Health and Social Affairs – Spain

Total budget: 1 994 414.72€ (EC co-funding 80%)
## Project Structure

<table>
<thead>
<tr>
<th>WP4</th>
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<tr>
<td><strong>State of the Art Social Care Provision for RD patients</strong></td>
<td><strong>European Network Resource Centres for RDs</strong></td>
<td><strong>Pilot of integrated &amp; personalised social care provision</strong></td>
<td><strong>Evaluation of the pilot social experimentation</strong></td>
<td><strong>Evaluation of the economic impact of the innovative partnership</strong></td>
<td><strong>Social Policy innovation based reforms</strong></td>
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<tr>
<td>EURORDIS</td>
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<td>APWR RPWA CJSJ</td>
<td>ZSI</td>
<td>KI</td>
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### WP1 Coordination (MSSSI, Finovatis)
WP2 Evaluation (IER)
WP3 Communication & Dissemination (EURORDIS)

### Main Applicant
**MSSSI** Ministry of Health and Social Affairs - Spain - Aitor Aparicio García

### Co-Applicants
**Finovatis** – France - David Koubi
**IER** Inštitut za Ekonomsko Raziskovanja – Slovenia – Valentina Rupel
**EURORDIS** – France – Raquel Castro
**APWR RPWA** Asociatia Prader Willi din Romania (NoRo) – Romania – Dorica Dan
**CJSJ** Regional County Sălaj – Romania - Monica Avram
**ZSI** Zentrum für Soziale Innovation – Austria - Ursula Holtgrewe
**KI** Karolinska Institutet – Sweden - Peter Lindgren
Project Concept

Pilot implementation
- At NoRo Resource Centre for rare diseases
- Implementation of case management for rare diseases
- Romania, 2017-2018 (18 months)
Project Objectives

• **Assessment of social needs of people living with a RD in Europe & analysis of care models in MS** (Austria, France, Hungary, Luxembourg, Romania, Spain, Sweden, UK);

• **Proposal of an innovative care pathway:**
  • Implementation of a pilot in Romania
  • Evaluation of the socio-economic impact and cost-benefit analysis of the care model
  • Analysis of opportunities to upscale the model to other MS and beyond RDs

• **Creation of the European Network of Resource Centres** & exchange of good practices between social services for rare diseases via workshops

• **Strengthening partnerships between stakeholders**: creation of an Advisory Group with competent authorities
## Project Events

<table>
<thead>
<tr>
<th>Date</th>
<th>Place</th>
<th>Event</th>
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</thead>
<tbody>
<tr>
<td>8-9 Sept 2016</td>
<td>Gothenburg</td>
<td>Workshop on Improving Integrated Care for People Living with Rare Diseases and Complex Conditions</td>
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<tr>
<td>6-7 Oct 2016</td>
<td>Vienna</td>
<td>Workshop on Scaling Innovative Care Delivery for Rare Diseases &amp; Complex Conditions</td>
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<tr>
<td>1-2 June</td>
<td>Cluj-Napoca</td>
<td>Workshop on Advancing Holistic &amp; Innovative Care for Rare Diseases &amp; Complex Conditions</td>
</tr>
<tr>
<td>12-13 April 2018</td>
<td>Oslo</td>
<td>Workshop on Creating a Sustainable Environment for Holistic &amp; Innovative Care for Rare Diseases &amp; Complex Conditions</td>
</tr>
<tr>
<td>Sept 2018</td>
<td>Brussels</td>
<td>Final conference</td>
</tr>
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Details and presentations available at:  
http://innovcare.eu/events/
Engaging with policy makers

✓ INNOVCare Advisory Group
  • 17 representatives from 14 European countries
  • National/regional competent authorities - mix of health and social
  • Goal:
    • Promote better dissemination of the project to policy makers
    • Engage on up-scaling the pilot/similar model to their countries
    • Advisory Group will attend 3 workshops of the project

✓ Link to Commission Expert Group on Rare Diseases
✓ Link to RD-Action project (2015-2018), policy work package
First Europe-wide survey on the social impact of rare diseases
First Europe-wide survey on social impact of rare diseases

Juggling care and daily life: The balancing act of the rare disease community

• Carried out via Rare Barometer Voices
• Over 3000 patients and carers involved
• 802 diseases, 42 countries
• Performed in 23 languages
First Europe-wide survey on social impact of rare diseases

Key results:

• Rare diseases have a serious impact on everyday life
• Significant time and care burden for patients & carers
• Impact on work-life: absence from work, stop or reduce professional activity, facing loss of income
• Patients and carers are badly informed about their rights
• Clear lack of communication between service providers
• Social services badly prepared to support people with a rare disease

Report with analysis of key results and annex with full results
INNOVCare pilot of case management & evaluation of its social and economic impact
INNOVCare pilot – NoRo Resource Centre

- Zalau, County of Salaj, Romania
- **One-stop-shop style of service**
- Recognised as social and healthcare provider *(Centre of Expertise for rare diseases)*
- **Providing services to patients** at local, county and national level
INNOVCare pilot - Summary

Regional case managers hired by NoRo resource centre Romania:
• To bridge the gaps in coordination between health, social and local services
• To reduce care burden for patients and families

Time frame:
• 18 months, 03/2017 - 08/2018
• 9 months for each patient/family

Target population:
• Patients and families: rare diseases & complex conditions
• 118 cases
• Current beneficiaries of NoRo & new ones

Geographical scope: region of Salaj, Romania

Resources and service provision:
• Number of case managers employed: 4
• Nr. of simultaneous “cases” per case manager: 30
• Profile of case managers: 2 social workers, 1 lawyer and 1 special education teacher
• Service focused on key areas to have meaningful results
INNOVCare pilot – Possible roles of the case manager

- Single and stable point of contact
- Listen, inform, support and empower patients and families
  - Providing knowledge/tools & informing about existing resources
  - Encourage health literacy and compliance to treatments
  - Relief the burden of care provision for patients and families
- Assessment/monitoring of needs & being an observatory of those needs
- Holistic and patient-centred care planning and care co-ordination:
  - Identify resources available in the territory - services and support
  - Referral to and speed up access to services and support
  - Simplify care pathways, ensure continuous support, support navigation for patients/families and professionals
- Hub of information and knowledge
- Inform, support and empower professionals involved in care provision
- Facilitating coordination between services and networks of service providers
- Prevention of avoidable high risk situations & limit over-use of health services if not needed
- Develop working methods that support empowerment of patients and families
The INNOVCare evaluation design

How does the INNOVCare intervention impact the quality of lives of those who benefit from it? What’s the economic impact?

A basic two-condition repeated-measures design / rotation design

- **Sampling**: random proportionate stratified sampling, based on set of variables
- **Randomisation**: stratified random assignment - random allocation of participants into the 1st and 2nd cohorts based on set of variables; simple random allocation to the case managers;
- **Ex-post assessment of the randomisation procedure**: checking balance of the two cohorts
RareResourceNet

European Network of Resource Centres for Rare Diseases
RareResourceNet

Advancing holistic high quality care and services for people living with rare diseases across Europe

Resource centres: a one stop shop style service designed for people living with a rare disease and their carers

- Complementary to health care and social services
- Holistic care and support

https://innovcare.eu/social-services/rareresourcenet/

The gathering of services in this network is possible following the mapping of specialised social services for rare diseases performed within the European Joint Action for Rare Diseases (EURCERD Joint-Action, 2012-2015). RareResourceNet subscribes to the European Commission Expert Group Recommendations to Support the Integration of Rare Diseases into Social Services and Policies (2016) & 2030 Agenda for Sustainable Development adopted by the United Nations (2015).
INNOCare gives a voice to the social and everyday needs of people living with a rare disease and addresses the need for coordination between service providers in European Union Member States.
Innovative Patient-Centred Approach for Social Care Provision to Complex Conditions

Thank you

www.innovcare.eu